

# In aid of Alfies Appeal



## ALFIE'S STORY

At the age of 8 weeks, like many babies, Alfie suffered from minor nappy rash. During the application of cream, we discovered a very small lump in the crease of his left groin area. We were referred to a pediatric doctor who was equally baffled by the lump.

Over the course of the next six months, we continued with frequent visits to the pediatrician and as time went on, the lump increased in size. From ultrasound it appeared to be an infected lymph node and we were then referred for removal. The surgeon's first intention was to biopsy the lump or remove during the procedure if possible. Our baby boy at the age of 10 months was to have his first General Anaesthetic a very worrying prospect for any parent. The surgeon advised the majority of the lump was removed and it was then sent away for further testing.

The pathologist's report was inconclusive and it was then passed to Great Ormond Street for further review. The diagnosis was a myofibrosis tissue based tumour. We were advised this was a rare benign tumour but due to the incompleteness of the surgery localised reoccurrence may be experienced. Within 8 weeks, 2 lumps appeared in the same area and we were immediately referred for Surgery at Great Ormond Street Hospital. Alfie underwent surgery for complete removal of the lump and surrounding tissue. The operation was successful and within a couple of hours Alfie recovered and was playing, back to his normal self. The lumps were then sent for further investigation.

On the 27th May 2009 we were advised that despite the previous diagnosis the pathology had changed and Alfie had a Sarcoma of the tissue.

To be sure of no more reoccurrence, Alfie was given six months "mild" chemotherapy. This was a struggle for him and resulted in many admissions to our local hospital. Alfie was due to finish treatment on the 21st November 2009 and we couldn't wait to get the year of 2009 behind us and get our lives back to normal.

Alfie's end of treatment scan detected a new small lump above Alfie's right kidney. The first concern was of reoccurrence of the Sarcoma although due to the location, the consultants wanted to Biopsy. The lump was biopsied and confirmed as NEUROBLASTOMA to the complete surprise of everyone.

Early detection, the size of the tumour and Alfie's age, should have indicated stage 1 Neuroblastoma which we were advised would be straight forward to treat. After several weeks praying and hoping for no further spread of the tumour, on 21st December 2009 when our son was one year and 8 months old, our lives were to change forever. Alfie presented with widespread disease and was unable to walk. He had bruising around his eyes and a bone marrow aspirate confirmed diagnosis. We was then given the worst news and we felt complete numbness. We had a definitive diagnosis and despite our world now being torn apart we had to accept the news. Alfie was confirmed and diagnosed with the highest level - Stage IV Neuroblastoma (Stage Four MYCN amplified). Alfie has wide spread disease in all areas as expected with this type of disease. The main (primary) Neuroblastoma tumor is relatively small and within his right adrenal gland; its approximate measurements 1.8 x 2cm.



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The treatment of High-Risk Neuroblastoma is harsh and unrelenting but is necessary to combat this aggressive cancer. Children who achieve clean bone marrow and MIBG tests results after the initial rounds of chemotherapy must undergo a stem cell harvest, surgery to remove any solid tumours, high-dose chemotherapy to wipe out their bone marrow and stem cell rescue to transplant the previously harvested stem cells back into the body to allow new bone marrow to be grown. Finally they will have radiotherapy and then 6 months of oral chemotherapy to mop up any undetectable minimal residual disease. Even after all this, the chance of relapse still remains high.

On Christmas Eve 2009, Alfie had a triple lumen line fitted directly into his main artery near his heart for drug administration. He underwent 70 days of intensive chemotherapy, endured invasive testing procedures and had a number of blood and platelet transfusions. Despite the toxicity of this protocol he remained strong.

Despite the obvious positive signs of Alfie looking really well, him walking and the clearing of the bruising around the eyes, Alfie did not respond well enough to the treatment. At the 40-day stage, his bone marrow aspirates test was clear. At the 70-day stage, the test was more invasive and a test of Bone Marrow aspirates and Trepine still showed signs of disease and the MIBG scan showed the disease was still present. Without being clear of detectable disease Alfie could not move forward to the next stage of treatment. We had then to undergo two more 7-day cycles of a high-risk chemotherapy regimen called 'TVD', to try and get him to the next stage. Another series of bone marrow tests, MRI and MIBG scans were to follow in May. In early in June 2010, Alfie relapsed and developed a new tumor in his left upper-jaw. Our oncology consultant confirmed to us that due to Alfie's relapse the disease was no longer curable. We were given the option to either go home, try another chemotherapy combination (which probably would not work) or try and enter Alfie to a phase-1 trial (which was only to determine dose levels and he may not qualify for).

We decided that we needed to follow the further research and support from others who had similar experiences. We dropped everything and travelled directly to a cancer clinic of alternative treatment in Mexico. Unfortunately, Alfie was unable to stay at the clinic and had to urgently return home as the relapsed tumour in Alfie's jaw spread in to his mouth and got out of control. We went directly to Great Ormond St. where he had emergency surgery. We were very close to losing Alfie here; this was an awful low point.

Alfie was then moved to University College Hospital in London for radiation to the face and spine, where a further tumor developed. This was to alleviate pain and control the rapid growth and hopefully allow Alfie the chance to walk again. We had no option but to move to this aggressive treatment due to the rate of tumor growth in critical areas. Every second of every day, we continued fighting to cure our beautiful baby boy from this horrid disease. We never gave up hope and our friend's, families and local community were all out there trying so very hard to help us. This really helped us and gave us courage, strength and belief.



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We finally returned home to spend time with Alfie away from the Hospitals and the relentless intervention at his favorite place.

He peacefully passed away without any pain on the 29th July, 2010 at 10am. He was where he wanted to be; cuddled up tight with his Mummy and Daddy.

During Alfie's gruelling treatment, we found help from 'complementary' treatments, and had the support from a Nutritional Therapist. It wasn't long before we could see the benefit of the strategies. Alfie lost no weight, suffered no infections, unlike fellow patients who suffered for months, he suffered from mild mucositis for only a few days, his Candida infection was also cleared in days, rather than becoming a systemic infection. We felt empowered and worked so hard to support Alfie and although he sadly lost his courageous battle to cancer, we firmly believe the fact he died without pain, without infections and without suffering was solely as a result of their regime based around good nutrition, nutritional supplementation, clean water and air free of toxins.

For this reason we will not go back to life as it was; we had drawn so much from the support and want to put something back. We had already set up a fund for Alfie to pay for treatment outside of the UK. Sadly Alfie died before this was possible, this fund will now be used to the set up of a study and for the creation of a recipe book for Children with Cancer and other conditions. Alfie's story has touched the heart of so many and the fund has continued to grow. All of this money is being donated to the set up of other families affected by childhood cancers.

**The spirit of Alfie will live on and help other children.**